Medicine in the Internet age. The rise of the network society

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Invited paper

Summary

When social scientists began analyzing the socio-cultural impact of the Internet, health emerged as one of the areas in which the Internet has become a key means of communication and cultural expression. It is no exaggeration to say that the Internet is bringing about a structural transformation of the cultural practices and organization of health systems. This is the so-called *online revolution of health systems*. The Internet has both the usership and the technical prerequisites to be an ideal medium for promoting health-related education and support, but what makes the Internet the health medium *par excellence* is the fact that it is the mode of cultural expression and output most compatible with the transformations that have taken place and are taking place in our society: that is, with the rise of the network society. In this paper, I discuss the opportunities and challenges arising from the transformation of health systems into patient-centred networks.

KEY WORDS: health systems, Internet, medical information, social network, online community.

The online revolution of health systems

Data on the diffusion of the Internet are not always precise or reliable. Often skewed by emotive or ideological assessments, they fluctuate between futuristic exaltation (*e-xaggeration* to use the term coined by *The Economist*) and hypercritical downplaying of the phenomenon.
This ambivalence towards the Web reflects a very human sense of bewilderment and lack of control in the face of this seemingly technology-driven process of social and cultural change. Fortunately, the gaps in our knowledge (often filled with futile chit-chat and haphazard analyses) are now being remedied by a growing number of rigorous studies that are allowing us to assess the Internet phenomenon on the basis of documented and analytical data.
Published by Network Wizard and RIPE, recent European hostcount data (i.e., numbers of permanent IP addresses, considered a reliable index of the level of Internet use) showed a 100% increase in the three-year period 2000-2003 (1). Italy was the country recording the largest growth and is now the European leader in terms of the absolute number of hosts (its 5,460,578 representing 16.2% of the European total). Italian domains rose from 90,000 in 1999 to over 1,000,000 in 2004. (For fascinating and up-to-date statistics on the Internet, visit www.nua.com/surveys/ or www.clickz.com/stats/).
According to the most reliable estimates, approximately 13,000,000 Italians – this figure corresponds to around 25% of the country's population, and has risen by 50% in just three years (source: Eurisko) – are Internet users, and the trend is still one of constant, although irregular, growth (1). It is also worth pointing out the increased spatial penetration of the Internet: the geographical fragmentation of the phenomenon, which was attributable to differences in wealth, social status and accessibility to this technology, is now gradually disappearing; the Internet is becoming a resource available to more and more people, although not yet to all. The European Information Technology Observatory and Nua estimate that Internet users in Italy account for 33-40% of the total population, a percentage higher than the European average but still much lower than the level recorded in northern European countries and the USA, where Internet users account for well over 50% of the population (1). It is interesting to remark (source: Nielsen Net Ratings) that 2003 saw a 28% increase in the number of over-55s accessing the Internet in Europe (+32% in Italy, where around 10% of all users are "silver surfers").
Available observational data show, beyond doubt, that the Internet is continuing its rapid and dramatic invasion of people's lives. At this point, it is important to recall that the Internet is fundamentally a "new sphere of communication", and given that conscious communication is the essence of human activity, "all areas of social life are about to be modified by the increasingly widespread use of the Internet" (2).
Our analysis, at this point, naturally shifts to the question of the "quality" of Internet use. What are cyberspace travellers looking for? For which socio-cultural sectors is the Internet becoming a primary medium?
When social scientists, applying scientific methods, began analyzing the socio-cultural impact of the Internet, a situation emerged that was, to many, unexpected. It was found that health is one of the areas in which the Internet has become a key means of communication and cultural expression. It is no exaggeration to say that the Internet is bringing about a structural transformation of the cultural practices and organization of

health systems. This is the so-called *online revolution of health systems.*

In the United States the extent of this phenomenon has been known for some time, thanks to the pioneering work of Pew Internet and the researchers at Georgetown University (www.pewinternet.org/ ; www.healthprivacy.org). The findings of their studies provide real food for thought. In 2000, 52 million Americans, or 55% of those with access to the Internet – this figure rose to 62% in 2002 – used the Web to find health-related information or services and, of these, 92% considered the information they obtained *useful and relevant*; 68% declared that they *had been influenced by it* and 62% reported that it had made them *better able to take care of themselves* (this latter figure was up to 74% in 2002) (3). Overall, the researching of medical information and services was the most frequent use made of the Internet, after e-mail and search engine use. Between 10 and 30% of Americans have participated in *online support groups* (3) and in April 2004, Yahoo/Groups alone hosted over 25,000 electronic support groups. This kind of participation is increasing exponentially and is extremely widespread among the chronically ill.

In the European Union, data on health-related Internet use show marked differences between states, reflecting differences in the geography of the Internet and in the socio-cultural organization of the various countries (4). On average, almost one European in four (23%) uses the Internet for heath-related research (40% in The Netherlands and Denmark, 15% in Italy, Spain, and Greece) and 42% consider it useful, even though Europeans still appear to have greater faith in more traditional and direct channels (consulting one's doctor, pharmacist, etc.).

Finally, it has been calculated that, in 2003, as many as 6,750,000 health-related Internet searches were made every day (5).

In short, it appears clear that:

a) the Internet is becoming the preferred medium to obtain health-related information and actively influences people's behaviours, decisions and state of health;

b) patients are increasingly using the Web to obtain not only services, but also therapies. Given the nature of the medium and the current technical limitations in the transfer of more complex signals, such as video signals, these therapies are mainly psychotherapeutic and psycho-educational interventions.

At this point, it is necessary to look beyond the evidence and to try to analyze the causes underlying these phenomena. Our analysis shows that they are not simply passing trends or fashions, but in fact herald a radical transformation of the way in which health services and society itself are organized.

The network generation and the irresistible appeal of online medicine ("Welcome to the health network - help us to help you")

Medicine can, essentially, be regarded as an information-based human activity involving the transfer of knowledge, in various forms and ways, to an external user. From this perspective, looking for health-related information or services is, fundamentally, a quest to fill a knowledge gap and, as such, can be analyzed applying the same canons as are applied in any study of human information-seeking behaviour.

Every time an individual sets out to find information, he sets in motion an iterative cycle comprising three stages (6).

The first of these stages is the *need for information,* that is, the acknowledgment of a gap in his knowledge. The second stage is the *search for information,* which also includes the selection of and interaction with information sources. The third stage is the *use of the information* obtained to solve the initial problem, or to increase his knowledge base. If the new depth of knowledge reached is still inadequate, the whole cycle starts round again.

The *need for information* stage is the one that, principally, determines the demand for health information and services. This demand has been increasing exponentially in recent years for three different reasons: i) the demand for information generally is increasing, as are the sources of access to it; ii) the traditional sources of health-related information, which are based on the clinical, hierarchical, unidirectional health operator→patient model, are breaking down. A consultation with one's GP now lasts an average of just 7 minutes, a specialist consultation lasts 14 minutes (3,7), and there elapse just 2-5 minutes between the patient's account of his problem and the prescription of a drug. (Unsurprisingly, the vast majority of patients leave their doctor's surgery feeling dissatisfied, with their need for knowledge unfulfilled); iii) a transformation of health services has begun that is based on responsible and increasingly broad involvement of the patient, as an active participant, in matters relating to his own health (8,9). He is called upon to make lifestyle changes and expected to be informed, so as to be able to make health choices with his doctor, rather than having decisions imposed on him. This is a self-help movement proper, for which the Internet is the natural sphere of expression.

In the context of this considerable need for health-related information, the particular characteristics and technical attributes of the Internet mean that, in the *search for information* stage, it is far superior to the other media. One need only consider that the Internet is extremely widespread, convenient, always available, and easy to use, and furthermore allows the user to remain anonymous; it also allows both interactive and proactive approaches, and offers the user a huge and up-to-the-minute choice, also putting at his disposal, almost in real time, the most recent scientific findings [it has been calculated that, until a decade ago, it took more that 70 years to take a discovery from laboratory to social application (10)].

In the *use of information* stage, too, the Internet offers considerable advantages over other sources. Indeed, in the "virtual reality" of the Web, which is both a medium and a means of communication, the user will find not only information, but also an extensive range of health services and personalized therapeutic solutions that can help him to solve his different problems.

We have seen, then, that the Internet offers many advantages in all three stages of medical help-seeking behaviour. However, these advantages are but the foundations of its enormous potential for use. What makes the Internet the health medium *par excellence* is the fact that it is the mode of cultural expression and output most compatible with the transformations that have taken place and are taking place in our society.

The current organization of society stems from the divorcing of place from sociality in the construction of communities and from the establishment of new models of social relations. Residential communities have been replaced by personalized communities, made up of single individuals who associate with one another on the basis of their specific interests, needs, choices, strategies, values and convictions. The web, or network, understood as an extremely flexible and adaptable construction, made up of many interconnected knots, has become our society's central and primary form of organizational interaction and of transfer of knowledge, and the Internet is its material infrastructure (11,12).
The network is based on an open, horizontal, multidirectional, interactive, "from-all-for-all" form of communication, and on a culture of cooperation and freedom of information that the growth of the Internet has allowed, for the first time, to expand on a global scale. As succinctly put by M. Castells (2), today's society is "individualism organized in a network" in which the bond between territory and socialization dissolves and life – real life – spreads into virtual space where online communication joins, and merges with, the offline variety.
Two spheres escaping this reshaping of man's systems of organization into knowledge-sharing networks are politics and education, both of which remain firmly bound to vertical/unidirectional organizational models (and this explains the growing popular disenchantment with them). The organization of health systems, on the other hand, is very much influenced by this process of change.
Indeed, our health system is progressively being transformed into a patient-centred network in which the patient is no longer just an external consumer. Instead, as an active member of a community, for whose processes he is in part responsible, he is both a valuable repository of knowledge and a health operator (13, www.fergusonreport.com). In this context, support groups, both online and offline, constitute the space in which the community comes together, socializes and shares its knowledge, transforming this into collective benefit and implicitly putting it at the disposal of the other networks. Welcome to the health network – help us to help you!

Cybertherapies and online support: the scientific perspective

We have seen, in the above paragraphs, that society and, with it, health systems have evolved into networks and communicate by means of network infrastructures. Support groups are the most typical expression of the network: they are already used by many people and, in the future, will be used by a great many more (14). As far as the supporters of "e-medicine" are concerned, the whole debate ends there. But for others, like us, who are convinced that technology must be subordinated to man, it becomes crucial to answer several questions.
How, in practical terms, do online support groups and, more generally, cybertherapies contribute to the clinical management of the patient?
In the last few years, a considerable number of groups have studied, scientifically, the usefulness and efficacy of psycho-educational interventions conducted via the Internet. The sectors involved are the ones in which, traditionally, support groups play an important role in the management of the therapeutic course: cancer, chronic illnesses, psychological illnesses, eating behaviour disorders, drug and alcohol addiction.
These studies, despite still being in a preliminary stage, have produced some encouraging data (14-16), which I summarize below:
a) the mechanisms within an online support group are the same as those created within a traditional group (mutual problem solving, swapping of information, expressing of experiences, catharsis, mutual help and assistance, empathy, etc.);
b) in all the groups studied, most of the participants declared that they were satisfied with the treatment;
c) it has been shown that, used alongside traditional treatment strategies, online support groups and, more generally, psycho-educational interventions conducted via the Internet may have positive effects on *physical wellbeing* (pain and pain management), *psychological wellbeing* (depressive symptoms, anxiety, negative reinforcement in abuse behaviours, perception/management of stress, emotional support), *isolation and social functioning, sense of worth, disability, quality of life, knowledge and practical management of the disease* (self-help, active/proactive attitude), *communication with physician and use of health resources, and compliance with the therapeutic regimen*;
d) the virtual communities offering support may generally be regarded as safe settings that will not generate side effects liable to endanger the health of those participating (15,16);
e) the Internet makes psycho-educational therapies available to individuals who, due to physical handicap or other practical difficulties (problems getting about, distance to service provider, social-working difficulties, etc.), would otherwise be unable to access them.
From a scientific viewpoint, the available data, despite deriving from a small number of not methodologically impeccable studies – Eysenbach et al., in a recent review, suggested that there is a need for more specific studies on this topic, given that available efficacy data are few and inconclusive (15) –, seem to confirm the technical correctness, the popularity and, in part, the efficacy of cybertherapies, as well as a high level of integration and complementarity between these and traditional therapeutic approaches.
But quite apart from the medium for the administration of cybertherapies, the fact that these are, indeed, therapies opens up another fundamental question: what are the limits and risks associated with their use and diffusion?

Primum non nocere. Act ethically

A critical review of the available scientific studies reveals that there are four possible areas of risk in the administration of cybertherapies.

Clinical and medical-care problems

At the present time, the psycho-educational intervention is based exclusively on written communication. The oral and non verbal components of communication play a fundamental role in the diagnostic process and the loss

of these elements could lead the inexperienced operator to commit errors, even serious ones, in his clinical management of a case (17). Achieving the desired tone in written language demands specific skills, because the written word can sometimes sound harsh and inflexible. This exposes participants to the risk of feeling rejected and, as a result, of suffering a loss of self-esteem and even emotional trauma. A second risk, in the absence of a traditional setting and direct professional supervision, is that participants may be induced, too soon, to lower their guard, and to send sensitive material into the blankness of cyberspace; this could increase their vulnerability and put their psychological health at risk. Work on sensitive material exposes participants to the risk of a crisis that the virtual setting may be ill-equipped to deal with (17). Another risk is that some subjects may be inclined to invest too much in the group, paradoxically isolating themselves from traditional relational points of reference and possibly giving up on, or failing to access other treatments (16). Furthermore, participant anonymity may encourage a proliferation of false identities, fabricated stories – even though Baym (18) has shown that most users create egos coherent with their offline identities – and excessively "jokey" participation. The absence of selection and the nature of online communication may mean that this medium attracts, in particular, individuals with marked socio-relational problems. Finally, the lack of specific training, in what is a developing sector, and the lack, too, of a universally accepted code of ethical practice and self-regulation (19) encourages improvisation and the participation of non qualified operators in technical, psycho-educational roles. Indeed, most online support groups furnish advice of varying quality, sometimes incorrect and biased, and most support offered does not go beyond the mere supplying of information (18,20,21).

Medical-legal problems

In the English-speaking world, which is a crucial sphere of reference for anyone interested in Internet-health system relations, the question of the protection of sensitive data, or rather of the confidentiality of health information, the threat to personal privacy, the maintaining of professional secrecy, and the administration of informed consent, has opened up an intense debate that has drawn in the scientific community and the law-makers and is causing concern to users (in the study "How the web helps Americans take better care of themselves" (3), 89% of those interviewed declared that they were worried over possible violations of their privacy). In the USA, 92% of websites collect the personal data of their users. These data are used – so they say – in an aggregated form to develop user profiles for marketing purposes (22). In this way, personal data could end up in the "human behaviours market". The risk of being catalogued for marketing purposes, which can have serious repercussions on an individual's insurance and employment prospects, is considerable. Europe and the United States seem to demonstrate opposing (restrictive versus less regulated) attitudes to the use of personal data, and the solution to this problem, being bound up with the very future of the Web, will not be easy to find.
Other current medical-legal problems concern the protection of minors and the protection and legal liability of operators working in the cybertherapies field (for a more in-depth analysis of the problem of technological overdevelopment and socio-institutional underdevelopment, of the threat to privacy, and of cryptotechnologies, read David Lyon's "The Electronic Eye" (23) and Reg Whitaker's "The End of Privacy" (24).

Technical problems

Using the Internet for therapeutic purposes presupposes familiarity with personal computers and a measure of technical knowledge; clearly, then, this risks cutting out a sizeable proportion on the population that might benefit from this approach (for example, the elderly, or people with mental handicaps or a low socio-educational profile). Some studies have also pointed out that the connections are often poor (generating the risk, in the case of synchronous therapies, that the patient may lose contact with the session) or excessively expensive (raising the question of the need to increase provider awareness of this problem).
For more on the "digital divide" visit: www.ntia.doc.gov/ntiahome/digitaldivide ; www.digitaldivide.com, or www.oecd.org.

Socio-economic problems

Looking ahead to a spread and, we hope, professionalization of the sphere of cybertherapies, it is only right to ask the question: who should pay for, or invest in this kind of online support? Should we favour spontaneous associationism or, instead, specific training, clear regulations, and remuneration for operators?

Concluding remarks

The Internet belongs to those who create it. In praise of chaos

Those who have been interested and patient enough to follow these arguments thus far will have learned that there exists a new form of social interaction: the online society that, on the basis of the transfer of knowledge, is transforming and revolutionizing all spheres of human activity, medicine first and foremost. As we have seen, this radical change is presenting opportunities and challenges, some of which are risky. There is the risk that we may lose our humanistic culture, that "calculating thought" will take hold, that information will prevail over knowledge. There is the risk that we will see a strengthening of a technical rather than anthropological approach to medicine, which will be market-oriented rather than guided by the interests of men (25). There is the risk that we may lose our fundamental freedoms (the network infrastructure can be monitored), and there is the risk of exclusion and of new forms of social outcasting. Finally, there is the risk of increased bewilderment and confusion and of the birth of new divisions and new forms of discrimination (a distinction is already made between e-friendly and non e-friendly health professionals and between e-literate and non e-literate patients). If, however, we can manage to shake off our diffidence towards the new, and avoid allowing prejudice to close our minds, then we will be able to see clearly

the unique opportunity offered by this new culture, based "on interactivity, on personalization and on the development of autonomous capacity for learning and for thought" (2). In the medical sphere, this may be translated into: increased user knowledge and collaboration, the bringing down of barriers preventing patients from gaining access to adequate care, the development of easier, exchange-based physician-patient communication, the development of personalized medical management programmes, tailored to the individual's needs and expectations, the spread of a culture of solidarity in the fight against disease, the trans-social spread of socio-educational and prevention programmes, the creation of a strong, well-informed force to counterbalance the excessive power of the pharmaceutical industry, and more functional and efficient health service delivery. The outcome of these challenges depends to a great extent on informed, conscious, and positive use of the Internet. In the words of the American Supreme Court in June 1997: "Just as the strength of the Internet is chaos, so the strength of our liberty depends upon the chaos and cacophony of […] unfettered speech". All that remains to do is enter the Internet and participate. The Internet belongs to those who create it: we are the Internet.

References

1. Gandalf. Pensieri sulla rete e sulla comunicazione (2005). People on line in Italy. www.gandalf.it/data/data3.htm (consulted 16 May 2005)
2. Castells M. The Internet Galaxy: Reflections on the Internet, Business and Society. New York/London; Oxford University Press 2001:45-90
3. The Pew Internet & American Life Project. (2000). The online health care revolution: how the Web helps Americans take better care of themselves. http://www.pewinternet.org/pdfs/PIP_Health_Report.pdf (consulted 16 May 2005)
4. Spadaro R. European Union Citizens and Sources of Information about Health (Eurobarometer 58.0). Brussels; The European Opinion Research Group (EORG) 2003 http://europa.eu.int/comm/health/ph_information/indicators/pub_indic_data_eu.htm (consulted 12 May 2004)
5. Eysenbach G, Kohler C. What is the prevalence of health-related searches on the World Wide Web? Qualitative and quantitative analysis of search engine queries on the internet. AMIA Annu Symp Proc 2003:225-229
6. Choo CW. The Knowing Organization: How Organizations Use Information to Construct Meaning, Create Knowledge, and Make Decisions. New York; Oxford University Press 1998
7. Jadad AR, Rizo CA, Enkin MW. I am a good patient, believe it or not. BMJ 2003;326:1293-1295
8. Giddens A. Modernity and Self-Identity: Self and Society in the Late Modern Age. Cambridge; Polity Press 1991
9. Loader BD, Muncer S, Burrows R, Pleace N, Nettleton S. Medicine on the line? Computer mediated social support and advice for people with diabetes. Int J Soc Welfare 2002;11:53-65
10. Health information for quality improvement act. http://www.oipa.od.nih.gov/legislation/108/pensinglegislation/healthinformation.asp (accessed May 2005)
11. Wellman B. Networks in the Global Village. Boulder (Col); Westview Press 1999:331-366
12. Wellman B. Physical place and cyberplace: the rise of networked individualism. International Journal of Urban and Regional Research 2001;25:227-252
13. Ferguson T. Online patient-helpers and physicians working together: a new partnership for high quality health care. BMJ 2000;321:1129-1132
14. Winkelman WJ, Choo CW. Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management. Health Expect 2003;6:352-358
15. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ 2004;328:1166
16. Eysenbach G. The impact of the Internet on cancer outcomes. CA Cancer J Clin 2003;53:356-371
17. Childress CA. Ethical issues in providing online psychotherapeutic interventions. Journal of Medical Internet Research 2000;2:E5
18. Baym N. The emergence of online community. In: Jones S ed Cybersociety 2.0: Revisiting Computer-Mediated Communication and Community. Thousand Oaks (Cal); Sage 1998:35-68
19. American Psychological Association. Services by telephone, teleconferencing and internet. A statement by the Ethics Committee of the American Psychological Association. 1997 http://www.apa.org/ethics/stmnt01.html (accessed March 2004)
20. International Society for Mental Health Online & Psychiatric Society for Informatics ISMHO/PSI. Suggested principles for the online provision of mental health services 2000. http://www.ismho.org/suggestions.html (accessed September 2004)
21. Childress CA. The holding relationship in cyberspace. 1999. http://www.geocities.com/Yosemite/Gorge/8251/holding.html (accessed February 2004)
22. Lessig L. Code and Other Laws of Cyberspace. New York; Basic Books 1999
23. Lyon D. The Electronic Eye. The Rise of the Surveillance Society. Polity Press 1994
24. Whitaker R. The End of Privacy. New York; The New Press 1999
25. Galimberti U. Psiche e Techne. L'uomo nell'età della tecnica. Italy; Feltrinelli 1999